



Take control of your care.

A toolkit for people with IBD, to help you communicate confidently with those involved in your care



This toolkit has been designed with people living with Inflammatory Bowel Disease (IBD) who receive their care at Sheffield Teaching Hospitals, as part of The Health Foundation-funded AWARE-IBD project. It has been designed to help you communicate confidently with those involved in your care, to make sure you get the best results for you.

The toolkit has been developed in collaboration with and with the support of the Sheffield IBD team. It's important to the IBD team that people with IBD feel comfortable to express themselves fully within the service, to communicate effectively with the team and to be satisfied with their consultations.

Thank you to everyone who contributed to this toolkit.

This is not a guide to IBD. It is a toolkit to help you communicate confidently with your IBD team.



Contents

Getting your voice heard: an introduction to self advocacy	4
Knowledge.....	6
Useful resources	
What do I need to know?	10
Knowing and using your rights	
Communication.....	12
Appointments journal	
Preparing for appointments	
Describing your symptoms	
Other communication tips	
Assertiveness skills	20
Working with your IBD team	21
Example scenarios	
What to do if you are not happy with your care	23
Top tips: a summary	24
About AWARE-IBD	26

Getting your voice heard: an introduction to self advocacy

As you are the expert in your own health and wellbeing, you should be fully involved in making choices about your treatment and care. It is also very important that the people involved in making decisions about you really hear what matters to you.

There will times in your life when you will particularly want to be listened to - but you should be able to get your voice heard and say what you think all of the time. Negotiating for what you want, so that you have more control over your life, is called self-advocacy.

Self-advocacy means that you will get your chance to:

- say what you think and feel
- make choices and decisions that affect you
- be heard so you can speak out for your rights
- work together to plan the best outcomes

However, self-advocating is not always an easy thing to do. People don't always feel confident telling health professionals what they would really like, and they can be worried about speaking out.

This toolkit has been designed by people living with IBD and the Sheffield IBD team to help you communicate confidently with those involved in your care to get the best results for you. It can support you to think about, and build, the skills you need to self-advocate.



What do I need to be able to advocate for myself?



Knowledge

If you don't have the information to help develop your views or don't know where to find it, it will be very difficult to explain them to others. This toolkit will help you find the information you need.

Communication and listening skills

These are essential to making sure your voice is heard.

Communication is more than just an exchange of information. Take time to check your understanding by asking the questions in a different way, so you can be sure that you've understood.

Assertiveness skills

Assertiveness is about saying what you want, but in a way which also respects the rights and feelings of others. Being able to assert your voice and ask questions or talk confidently about your concerns will help others to know how to support you. Remaining respectful of each other allows you to hold clear and concise conversations.

Working together with your IBD Team

At times, there may need to be some negotiation to reach an agreement on your care. It's important to explain what matters to you and find ways to achieve that, or to get as close as possible to it.

You know how your condition impacts your life. Your IBD team are experts in treating the condition in a wide range of individuals. It's really important to work together. By discussing what is possible, you'll be able to agree a plan that you are both happy with.



Knowledge

When others are involved in making decisions about you, it's important that you have as much information as possible too. There are a number of ways you can find out more about your own situation.



Sheffield IBD Centre

You can get in touch with your IBD team by calling 0114 2712209 on Mondays to Fridays 9 - 11am.

At other times you can leave a voicemail message which will be responded to within one working day.



For more general information
you can visit the website:
sheffield-ibd.sth.nhs.uk



Crohn's & Colitis UK

The Crohn's & Colitis UK website and helpline can provide up-to-date, evidence-based information and can support you to live well with Crohn's or Colitis.

The helpline and website can provide information on a range of subjects including:

- managing symptoms
- medication
- diet
- tests and diagnosis
- wellbeing and mental health
- employment
- disability benefits
- sex and relationships

Crohn's & Colitis UK can help you find support from others from the Crohn's and Colitis community. They also signpost to sources of expert advice on disability benefits and options for specialist emotional support.

Website: crohnsandcolitis.org.uk

Phone: 0300 222 5700

Email: helpline@crohnsandcolitis.org.uk

LiveChat on their website

Virtual social events



These provide opportunities to get to know other people in an informal setting, share experiences and potentially learn from others, but they are not intended to provide medical or professional advice. You may find just being with other people and realising that you are not alone can be reassuring. There are lots of ways to connect with people who understand what you're going through.

Crohn's & Colitis UK local networks

These support educational, awareness raising and fundraising activities. Family, friends and colleagues are also welcome at these events. You can also share your experiences with others, and find out news on Facebook, Twitter and Instagram.

Reliable sources of information on the internet

As well as the Crohn's & Colitis UK website crohnsandcolitis.org.uk/info, other charities that provide information include:

CICRA: better lives for children with Crohn's and Colitis: cicra.org

Ileostomy and Internal Pouch Association (known as IA): iasupport.org

The NHS website for England (www.nhs.uk) is the UK's biggest health website, with more than 50 million visits every month. It is designed to help you take control of your health and wellbeing by providing safe, accurate and up-to-date information.

Social media is also an important part of the NHS website service:

Facebook: facebook.com/NHSwebsite

Twitter: twitter.com/NHSuk

YouTube: youtube.com/user/NHSChoices

Researchers at The University of Oxford have worked with people living with IBD to co-produce a website on sexual wellbeing and IBD.

Sex drugs and toilet rolls:
sexdrugsandtoiletrolls.com



Libraries

You can contact your local library which helps to promote healthy living by providing self-management support, engagement opportunities and effective signposting. They can help you find information in print and online.

Records of your own health consultations

Making a note of the conversations you have with your IBD team can be really useful for referring back to later. You can keep records in your personalised care plan (if you have one) or you can use Crohn's & Colitis UK My appointments journal to record this information: crohnsandcolitis.org.uk/appointments.

After your appointment

How did it go?

My blood test results look normal so I'll have to have an endoscopy to check. Dr gave me a prescription for some enemas for now to see if that helps. She gave me some information sheets on other medicines I could try next, so I'll book in an appointment next month to discuss these if the enemas don't help. She also said Crohn's & Colitis UK have a Local Network in the area where I can meet others with Crohn's and Colitis.

What needs to happen next?

• My health professional has agreed to:

Refer me to the hospital dietician and counselling service
 Arrange an urgent colonoscopy with the Endoscopy department

• I've agreed to:

- Start reading about the other medicines I may try next
- Try the enemas every night
- Arrange an appointment with my doctor for next month
- Join the Crohn's & Colitis Local Network

Weight:

Test results:

Bloods all normal

What do I need to know?

When you are researching or learning about something new, it can feel a bit overwhelming. As you go through the information, try to record or write down the most important aspects which seem to fit your own personal situation. This will help you recall, and use, the knowledge that matters to you.

Information should be available to everyone in the way that they need it. Often there will be a telephone number or website link for receiving information in alternative formats - this might be in easy read, another language or for someone to talk to you about it.

If you do not understand the information, ask for support. You have a right to have information in a way you can understand it.

Using the information

Once you have the information you can begin to use it to plan, to make a difference, or to ask questions in an appointment. You can also start to look at the skills you need to use this information most effectively to get your voice heard.

Remember you can contact organisations like Crohn's & Colitis UK for information and support, and local advocacy groups which support people to be heard in decisions about their health, care, and wellbeing.

Knowing and using your rights

To be a good self advocate you need to know about your rights, and what you can expect from a service. IBD UK is a partnership of 17 professional bodies, royal colleges and patient organisations working together to improve care and treatment for everyone affected by Inflammatory Bowel Disease. Their main aim is to ensure that everyone with IBD has consistent, safe, high-quality personalised care, whatever their age and wherever they live in the UK. In 2019 they published the IBD standards, which define what good care should look like for people with IBD.

Here are some examples of the standards:

- IBD team – Patients should be cared for by a defined IBD multidisciplinary team led by a named consultant adult or paediatric gastroenterologist (Statement 1.1).
- Personalised care – A personalised care plan should be in place for every IBD patient, with access to an IBD nurse specialist and telephone/email advice line (Statement 7.1).
- Joined-up care – GPs should be informed of new diagnoses and the care plan that has been agreed within 48 hours (Statement 3.6).
- Diagnosis – Patients who are referred with suspected IBD should be seen within four weeks, or more rapidly if clinically necessary (Statement 2.2).
- Participation in decision-making – Patients should be supported to make informed, shared decisions about their treatment and care to ensure these take their preferences and goals fully into account (Statement 3.3).
- Living with IBD – All patients with IBD should be provided with clear information to support self-management and early intervention in the case of a flare (Statement 4.2).
- Considering all symptoms – Pain and fatigue are common symptoms for IBD patients and should be investigated and managed using a multidisciplinary approach including pharmacological, non-pharmacological and psychological interventions where appropriate (Statement 7.4).
- Going into the hospital – All IBD inpatients should have access to an IBD nurse specialist (Statement 6.9).
- Improving my service – Patients and parents/carers should have a voice and direct involvement in the development of the service (Statement 1.7).



You can download a full copy of the IBD Standards from ibduk.org.

Printed copies are also available on request from the Sheffield IBD Centre.

Communication

Your appointment

This might be by telephone or face to face in a clinic. The consultation is likely to cover:

- any background that is relevant to what's happening now
- what is happening now, including results of recent investigations, effects of recent treatment
- a plan for the future, both the immediate and possibly longer term

It's important that there is an opportunity to provide information that is important to you. Please ask to do so, for example by asking, "Can I add something?"

Appointments journal

Crohn's & Colitis UK has an appointments journal to help you get ready. crohnsandcolitis.org.uk/appointments

It has some useful tools to help you talk about how you are feeling, how to make the most out of your time with health professionals and focus on what matters to you. It includes tips on talking, handy questions and provides a space where you can make notes.

Good communication can make an important difference in expressing how your condition is affecting your life, and making sure people understand what matters to you.



Preparing for appointments

Being adequately prepared for appointments or telephone calls is very important, especially if you don't consider yourself a very confident communicator.

- Make notes beforehand to help you clearly communicate what you want to say. It can help to reduce anxiety and help prompt you to ask difficult questions.
- Aim to keep things as simple as possible and remember to focus on what's most important for you to get out of this appointment.
- Practise what you are going to say in the appointment and make sure that you have all of the relevant information to hand.

It's really important to make sure your message is heard, but sometimes what we are trying to say is not what the other person hears. This can cause frustrations and misunderstandings.

Before your appointment: Example

Who you're seeing: My Gastroenterologist

When: Tuesday 2pm

Where: Hospital - gastro outpatients

My main worries:

I don't think my medicine is working anymore because I've been in a lot more pain, and going to the toilet a lot more. It's making me really worried about leaving the house. More and more foods set me off now so I've been limiting what I eat. It's starting to make me feel really down as I don't have anyone to talk to who understands.


My mental health - I've felt



Poo:

6 times a day

 **Pain:** Around 7 on the pain scale on page 87

 **Fatigue:** Around 5 on the fatigue scale on page 87

What are your goals for this appointment?

Discuss an alternative treatment option

Get advice about what to eat

Information on support groups

It may sound obvious, but listening is the one communication skill that it can be useful to perfect. Being able to accurately receive and interpret messages is vital for good communication.

Your appointment is about you, so don't leave feeling confused or unsure.

- If you don't understand fully what your healthcare professional has said, ask them to explain it again.
- We know your appointment time is limited but try not to feel rushed.
- If you are finding it difficult to follow the conversation, ask for the information or advice to be repeated or told to you in a different way.
- You are likely to hear and read many new medical terms when you are diagnosed with Crohn's or Colitis. A glossary of terms, which lists many of the words you might come across when talking about IBD, can be found on the Crohn's & Colitis UK website.
- Their appointment journal has a list of 'Things your healthcare professional may say.' If you're not familiar with the terms being used, ask for them to be explained.
- If you are in a face-to-face meeting or on a video call and don't understand what you are being told, you could ask the healthcare professional to draw or mark up on a graphic of the gut to give you a visual aid.
- It's OK if there are times in the conversations when no-one is talking. This may give everyone chance to process what has been said. You should not be afraid to ask for time to think if you need it.
- It can be useful to repeat back what you've been told, just to check that you've understood the conversation.



Support in appointments

Remember, you can always take someone to your appointment with you to help you. It's also fine to make your own notes during an appointment.

If you need support in the form of a translator, or any other form of support to help get your voice heard or for you to be able to understand what is being said to you, please let your IBD team know.

If you need a British Sign Language (BSL) interpreter this can be arranged. You can request a particular interpreter, if it helps, although we can't guarantee that. This is arranged by the clinic booking team. When the IBD consultant, nurse specialist or the staff member requests your appointment, please make sure they also request a BSL interpreter with your preferred interpreter details, if necessary. Your clinic appointment confirmation letter will state that a BSL interpreter has been booked. If a BSL interpreter is required for other situations, for example for a planned telephone clinic or procedure, please discuss with the person that arranges the appointment.

Occasionally a BSL interpreter may cancel at short notice. Someone from the IBD Team will be in touch to rearrange your appointment as soon as possible.



Describing your symptoms

How are you feeling?

It can feel awkward and embarrassing to tell your IBD team how you feel, but they really need to know in order to support you well. Don't ever feel that what you are experiencing is not relevant. Tell them about any important aspects of your life, especially if this is something they might not be aware of, such as your sexuality and gender identity, and different life stages like pregnancy and menopause.

Although you are talking to professionals, you don't need to worry about using the proper medical terms. It's fine to use everyday language to talk about your experiences.

When it comes to describing your symptoms, there's no right or wrong way to say how you feel. It can feel strange to use emotional language, particularly if you have not done this before, but don't be afraid to say how bad things are for you. Here are some examples of how you might start to describe how you feel:

I'm worried about...

I can't...

I'm struggling to...

I'm not coping with...

My quality of life has got worse

I'm not happy with how my treatment is going

Remember: it's your body and you are the expert in how you feel.

Do not be afraid to ask for time to think if you need it, and repeat back what you have been told just to check that you've understood it.

It is OK to say no, or disagree, and to question anything that is said to you.

If you are not happy with your treatment talk to your IBD team. If you want to speak to someone outside the IBD team, you can talk to PALS.



Examples of symptoms

The diagram below shows some examples of symptoms that could be related to your IBD. You might want to ask about these.



You don't need to wait for your next appointment to raise a question about a new symptom. Call your IBD team on 0114 2712209.

Guide to pain scales

Using scales like these can make it easier to communicate how you are feeling.

⚡ Pain scale



- | | |
|-----------|--|
| 0 | No pain |
| 1 | Very mild – very minor annoyance |
| 2 | Discomforting – minor annoyance |
| 3 | Tolerable – annoying enough to distracting |
| 4 | Distressing – distracting but can ignore |
| 5 | Very Distressing – can't be ignored for more than 30 mins |
| 6 | Intense – but you can still do other activities |
| 7 | Very intense – hard to concentrate |
| 8 | Utterly horrible – physical activity limited |
| 9 | Excruciating – unable to speak |
| 10 | Unimaginable – can make you pass out |

Zz Fatigue scale



0

No fatigue
– able to do all normal activities.



1 2 3

Mild fatigue
– able to do most normal activities.



4 5 6

Moderate fatigue
– able to do some activities but need rest.



7 8 9

Severe fatigue
– difficulty walking or doing everyday activities.



10

Extreme fatigue
– needing to sleep or rest all day.

Other communication tips

We also express ourselves through our own body language, posture and eye movement. For instance, in a face-to-face meeting, it can be useful to try to maintain direct eye contact if this is comfortable for you, to show interest and engagement in the conversation.

It's normal to feel stressed or overwhelmed at an appointment. If this happens, you're more likely to misread what you are being told, or to send confusing nonverbal signals.

- take your time
- try to relax as much as you can
- close your eyes briefly and take some deep breaths
- keep your shoulders relaxed

Other useful tips can be to take something to hold in your hand, or, before the appointment, think about a particularly happy thought or memory you can recall if you are feeling stressed.

If you think you are likely to feel really nervous in your appointment, you might want to consider having someone with you. If you prepare beforehand, and practise together, they can help you remember all the areas which you want to discuss, and make sure you get any specific points across.

Make the most of the Crohn's & Colitis UK appointment journal to help you prepare for your appointment. Use their handy tools to help you talk about how you are feeling.

What you want to say is important.

Tell your team about anything that matters to you.



Assertiveness skills

Assertiveness is about saying what you want, but in a way which also respects the rights and opinions of the other person. It is based on honest and direct communication.

You are the expert on your own life, so you should feel confident about what you are saying. It is important to realise that being assertive also includes being able to:

- say no or disagree
- ask for more time to think about your choices
- consider your options, but if you are not happy with them, to say so
- question anything that is said to you

Life's challenges can be easier to deal with, and you may find it easier to tell people what you think you need, if you are feeling good about yourself, and know that you are good at things.

For example, sometimes people will compliment you and that makes you feel good and boosts your self-esteem. But you can also help increase your own confidence by believing in your own skills and abilities. A good tip is to think about the things you are good at and to recognise them - these can be from any area of your life. Focusing in this way can help give you the confidence to say what you want in your appointments.

Trying to focus on positive statements can help. So for example, practice saying "I can ..." "I will..." rather than "I can't" in your everyday life too.

If someone doesn't seem to be listening to what you are saying, or if you feel they are wrong, try to stay calm, assertive and confident. Repeat yourself clearly and politely, say that you don't agree with a particular point, and explain your reason.

Working with your IBD Team

There will be times in your healthcare appointments when you will need to agree on the next steps. To help with this process, think about your goals, and the things that you want and include them in your personalised care plan (if you have one) or just write a list putting the most important thing at the top.

Once you have listed your goals, it is important to consider the different ways you might achieve them. Think about:

- what could be achieved differently?
- if it was achieved differently, how would this make you feel?
- if you can't get exactly what you want, how much would be enough?

If you find yourself in a situation where you are put on the spot and have to negotiate there and then, you can always ask for more time to think. This will give you chance to prepare properly and discuss details with any other relevant people.

Look for the things that everyone agrees on. Consider any points on your list that you might be willing to give up if this means you can have more of the things at the top of your list.

Negotiating always involves an understanding and acceptance of what is possible.



Example scenarios

Imagine you're developing a flare, but you're worried about taking steroids again. Your doctor says:

“From what you are telling me, I had better put you on a course of steroids.”

Here are some ways that you might respond:

“Before we can do that, can I ask about the pros and cons of this medication?”

“I am worried about this as it will be my third lot in 18 months. Can I make another appointment, in case the symptoms die down and I don't need them?”

“I would like more time to discuss the medication with you.”

Imagine your condition has been getting worse and although your IBD team has changed your medication, your doctor says,

“If this doesn't get any better then a stoma may be the only solution.”

Here are ways you might respond:

“What are the risks associated with this surgery?” “What will the operation involve?”

“Please give me more information about having a stoma.” “How long will I need to stay in hospital after the operation?”

“Will this surgery affect my sex life?”

“Will this affect my ability to have children in the future, or how a baby might be delivered?”

Think about what questions you want to ask and put them in order, with the most important at the top of your list.

If you have a personalised care plan you could put the list in there.



What to do if you are not happy with your care

While most people's care and treatment goes well, sometimes things can go wrong. If you're unhappy with your care or the service you have received, it's important to give this feedback so improvements can be made.

In the first instance, it's always best to discuss your concerns as soon as possible with the IBD team. They may well be able to sort out the issue quickly.

Most problems can be dealt with in this way but, in some cases, you may feel more comfortable speaking to someone not directly involved in your care. Either way, you can be confident that making a complaint will not have a negative effect on your future treatment.

Who can support you with making a complaint?

Your hospital's Patient Advice and Liaison Service (PALS) provides a point of contact for patients who have a concern, and

- either don't know which member of staff or department to raise it with

or

- they feel that they need to speak to someone outside of the department, or ward, to which their concern relates



Contacting PALS can be particularly helpful if your issue is urgent and you need action immediately, such as a problem with the treatment or care you're receiving while you are in hospital.

You can get in touch with PALS by calling 0114 271 2400 on Monday to Friday from 9.30am - 4pm. At other times, you can leave a message which will be responded to the next working day. You can also email PALS at sth.pals@nhs.net.

Top tips

Use this quick checklist to refresh your memory about the key points in this toolkit.

As you are the expert in your own health and wellbeing, you should be fully involved in making choices about your treatment and care. It is also very important that the people involved in making decisions about you are really listening to you.

Self-advocacy

Self-advocacy means that you will get your chance to:

- say what you think and feel
- make choices and decisions that affect you
- be heard so you can speak out for your rights
- work together to plan the best outcomes

Knowledge

When people are making decisions about you, you will want to know lots about that situation. You can find information by:

- talking to the professionals
- looking on the internet at reliable sources, such as the NHS website
- visiting the library
- keep records of your own health appointments

Communication

When it comes to describing your symptoms, there's no right or wrong way to say how you feel. It can feel strange to use emotional language, particularly if you have not done this before, but don't be afraid to say how bad things are for you. Although you are talking to professionals, you don't need to worry about using the proper medical terms. It's fine to use everyday language to talk about your experiences. That way you will feel more comfortable.

To help get ready for your appointment, you might want to:

- make some notes
- ask a friend or family member to come with you
- practice what you want to say

Appointments journal

Crohn's & Colitis UK has an appointments journal to help you get ready. crohnsandcolitis.org.uk/appointments

It has some useful tools to help you talk about how you are feeling, how to make the most out of your time with health professionals and focus on what matters to you. It includes tips on talking, handy questions and provides a space where you can make notes.

It also includes some tools for communicating your symptoms, a useful gut diagram and an appointment guide that might help you to think about some other symptoms that you might have. It provides examples of how you might want to describe your pain, fatigue, bowel problems and poo, along with some great attention-grabbing phrases that encourage you to use emotional language to say how bad things are for you.

The journal provides a space for you to make notes of how you're feeling in between appointments and keep everything neatly in one place.

Working with your team

The IBD team are keen to work with you to achieve your goals. Consider what these are and discuss the different ways to achieve them with your team. You may want to use a personalised care plan to help you discuss this.



About the **AWARE IBD** project

Lead: Professor Alan Lobo, Consultant Gastroenterologist

Project manager: Ms Elena Sheldon

The aim of this 3-year project is to re-design IBD services, shaped by those who use them – people with Inflammatory Bowel Disease. The Inflammatory Bowel Disease Centre at Sheffield Teaching Hospitals is working with Crohn's & Colitis UK, and other local partners. This partnership is:

- Crohn's & Colitis UK
- Sheffield Teaching Hospitals NHS Foundation Trust
- The University of Sheffield
- Sheffield Microsystems Coaching Academy
- EpiGenesys
- VoiceAbility

While the project is being delivered in Sheffield, the learning from this project will lead to better outcomes for people who live with Crohn's and Colitis across the UK.

This toolkit was created with the support of VoiceAbility, who have been helping people to be heard in decisions about their health, care and wellbeing for over 40 years.



View this toolkit online and in translation

This toolkit about Inflammatory Bowel Disease (IBD) is also available online at voiceability.org/aware-ibd. You can use the website's toolbar to read the text aloud, show simplified information, or translate the words into your language.

 Read aloud or translate

ਸੀਐੱਚ ਰਿਪੋਰਟ voiceability.org/aware-ibd ਦੇ ਲੇਕਚਰ ਨੂੰ ਸੁਣਨ ਅਤੇ ਸਮਝਣ ਲਈ ਸਾਡੇ ਵੈੱਬਸਾਈਟ 'ਤੇ ਜਾਓ।

ਇਸ ਦਸਤਾਵੇਜ਼ ਦਾ ਪੰਜਾਬੀ ਵਿੱਚ ਅਨੁਵਾਦ ਕਰਨ ਲਈ voiceability.org/aware-ibd 'ਤੇ ਜਾਓ।

تجربة قراءة وإذاعة صوتية لـ voiceability.org/aware-ibd في اللغة العربية.

Odwiedź stronę voiceability.org/aware-ibd, aby przetłumaczyć ten dokument na język polski.

Vizitați voiceability.org/aware-ibd pentru a traduce acest document în limba română.

Visite voiceability.org/aware-ibd para traduzir este documento para o português.

Ewch i voiceability.org/aware-ibd i gyfieithu'r ddogfen hon i'r Gymraeg.





VoiceAbility

 0300 303 1660

 helpline@voiceability.org

 voiceability.org

 [@VoiceAbility](https://twitter.com/VoiceAbility)



About VoiceAbility

We make sure you're heard when it matters most. We've been supporting people to have their say in decisions about their health, care and wellbeing for over 40 years. We're an independent charity and one of the UK's largest providers of advocacy and involvement services.